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Carter, G., McLaughlin, D., Kernohan, G., Hudson, P., Clarke, M., Froggatt, K., Passmore, A., & Brazil, K. (2018). The experiences and preparedness of family carers for best interest decision-making of a relative living with advanced dementia: A qualitative study. *Journal of Advanced Nursing*, 74(7), 1595-1604. <https://doi.org/10.1111/jan.13576>

Published in:
Journal of Advanced Nursing

Document Version:
Peer reviewed version

Queen's University Belfast - Research Portal:
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The experiences and preparedness of family carers for best interest decision-making of a relative living with advanced dementia: A qualitative study

Gillian CARTER*, BSc, BSc, PhD, Lecturer in Chronic Illness, School of Nursing and Midwifery, Queen's University Belfast, Belfast, UK

Dorry MCLAUGHLIN, MSc, PhD, RN, Lecturer in Palliative Care and Chronic Illness, School of Nursing and Midwifery, Queen's University Belfast, Belfast, UK

W George KERNOHAN, BSc, PhD, Professor of Health Research, School of Nursing, Ulster University, UK

Peter HUDSON, PhD, RN, Professor of Palliative Care, School of Nursing and Midwifery, Queen's University Belfast, Belfast, UK; Director Centre for Palliative Care, St Vincent's Hospital & University of Melbourne, Australia

Mike CLARKE, BA, DPhil, Director of the Northern Ireland Methodology Hub, School of Medicine, Dentistry and Biomedical Sciences, Queen's University Belfast, UK

Katherine FROGGATT, BSc, PhD, Professor, International Observatory on End of Life Care, Division of Health Research, Faculty of Health and Medicine, Lancaster University, UK

Peter PASSMORE, BSc, MD, FRCP (Lond, Glasg) FRCPI, Professor of Ageing and Geriatric Medicine, School of Medicine, Dentistry and Biomedical Sciences, Queen's University Belfast, UK

Kevin BRAZIL, BA, MA, PhD, Professor of Palliative Care, School of Nursing and Midwifery, Queen's University Belfast, Belfast, UK

*corresponding author

School of Nursing and Midwifery, Queen's University Belfast, Medical Biology Centre, 97 Lisburn Road, Belfast, BT9 7BL, g.carter@qub.ac.uk, +44 (0)2890975762

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Preparedness of Family Carers

Conflict of Interest Statement

No conflicts of interest have been declared by the authors.

Funding Statement

Funding to undertake this study was received from the Health and Social Care Public Health Agency Northern Ireland, and The Atlantic Philanthropies. The funding source had no involvement in the study design, in the collection, analysis and interpretation of data, in the writing of the report; and in the decision to submit the article for publication.

Author Contributions:

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE*):

- 1) substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- 2) drafting the article or revising it critically for important intellectual content.

* <http://www.icmje.org/recommendations/>"

Acknowledgements

The authors wish to express their sincere thanks to all of the family carers who participated in the interviews.

ABSTRACT

Aim: To explore the experience and the preparedness of family carers in their caregiving role as best interest decision-makers of a relative living with advanced dementia.

Background: The prevalence of dementia is a global issue. The role of being a carer of a relative living with dementia does not necessarily lessen once they are admitted to a nursing home. Best interest decision-making including end-of-life care decisions need to be made and reaching these choices can be challenging. The preparedness of family carers in this role needs greater understanding.

Design: Descriptive qualitative study

Methods: During 2015 twenty semi-structured interviews were conducted of family carers of nursing home residents living with advanced dementia, then analysed using Braun and Clarke's thematic analysis.

Results: Three themes were identified: (1) Caring for someone living with dementia. The impact on the carer's holistic well-being and their experience of being a best interest decision-maker; (2) Accessing support. The influential nature of formal and informal networks; (3) Perceived knowledge and understanding of the dementia trajectory of carers and nursing staff.

Conclusion: The experiences and preparedness of informal carers is a reflection of their personal response, but the distress experienced highlights the significant need of adequate support availability and of enhancing nursing staffs' dementia expertise to maximise their role in facilitating best interest decision-making. This has significant implications for nursing practice and for service user and nursing staff education. Considering the global impact of dementia our findings have international relevance for similar nursing homes across the world.

KEY WORDS: carers, decision-making, dementia, end of life care, nursing, nursing home care, nurse education

SUMMARY STATEMENT

Why is this research needed?

- The prevalence of dementia is a global issue and a large proportion of society will be affected by having dementia themselves or by caring for someone living with the disease.
- Best interest decisions including end-of-life care decisions may need to be made on behalf of the individual living with dementia by the family carer and this can be challenging.
- The preparedness of carers to undertake the caregiving role needs greater understanding and this research will provide insight and guidance about the challenges and enablers.

What are the key findings?

- New insights are provided to the need for tailored support mechanisms to meet the specific requirements of the carer.
- Key challenges around the level of understanding and awareness of the dementia trajectory for carers and of healthcare professionals are identified.
- The significant role nursing staff can have in facilitating Advance Care Plan discussions and best interest decision-making has not reached its full potential.

How should the findings be used to influence policy/practice/education?

- There is a need for further education of the dementia trajectory for carers and nursing staff, allowing fully informed best interest decisions to be made for an individual with advanced dementia.

- Findings might be helpful to nursing home managers to recognise the significant role their nursing staff should have in holding advance care plan discussions with informal carers.
- The development of a psychoeducational care intervention for family carers with an embedded facilitated peer support should be a priority.

INTRODUCTION

This research addresses the experiences and preparedness of family carers in their caregiving role as a best interest decision-maker of a relative living with advanced dementia. Due to the global prevalence of dementia it is vital to understand the family carer experiences of this to inform the development of effective interventions to support them in their decision-making role and to determine the influential nature of nursing staff and other healthcare professionals.

Background

In 2015 there were an estimated 47million people worldwide living with dementia (Alzheimer's Disease International, 2016) and this figure is projected to double every 20years (World Health Organisation, 2012). Therefore, a large proportion of the global society will be affected by either having dementia themselves or by caring for someone living with the disease (Peacock, Hammond-Collins, & Forbes, 2014). A family carers' preparedness for this role refers to their readiness to provide care in contrast to their adequacy to do so (Schumacher, Stewart, & Archbold, 1998) as they may contend with a host of stressful situations (Gignac & Gottlieb, 1996) and caregiver burden is widely testified to have a negative impact on the family carers' own well-being (Etters, Goodall, & Harrison, 2008; Richard Schulz, Boerner, Shear, Zhang, & Gitlin, 2006). Ultimately, when the burden of care exceeds the capacity of the informal carer, nursing or residential home placement commonly ensues (Butcher, Holkup, Park, & Maas, 2001; Nikzad-Terhune, Anderson, Newcomer, & Gaugler, 2010).

The decision to place a relative into institutional care such as a nursing home can be complex and distressing for the family (Butcher et al., 2001; Ryan & Scullion, 2000; Yaffe et al.,

2002) as they must now trust others with the care (Shanley, Russell, Middleton, & Simpson-Young, 2011). A sense of relief and reduced stress may follow, but this can also be accompanied by guilt, anger and depression (Brodaty & Donkin, 2009). A report by the National Academies of Sciences, Engineering and Medicine in the United States (US)(R. Schulz & Eden, 2016) provided recommendations for family caregiving of older adults and demonstrated that their roles varied significantly across the course of caregiving and was conceptualised as the ‘caregiving trajectory’. Therefore, entry into a nursing home does not necessarily depict the end of caregiving and decision-making for the relative but rather signals a new phase of their caregiving trajectory. Hence, the experience of care decision-making for family carers of a relative living with dementia may not necessarily lessen once their relative is admitted to a nursing home.

An individual with advanced dementia may no longer have the decision-making capacity with regards to their advance care planning choices, consequently family carers may be required to act as a best interest decision-maker, however their goals and values may conflict with other family members and with those of the individual with dementia (Karlavish, Quill, & Meier, 1999). This process is often complicated by time restrictions and carers generally have to accomplish this task whilst in a state of emotional and physical exhaustion (Lundh, Sandberg, & Nolan, 2000; Nolan & Dellasega, 2000; Wilder & Lanier, 2005). Therefore, support may be necessary for family carers not only with regards to the provision of care and the grief caused by witnessing the deterioration of their relative, but also to help them cope with their role as a best interest decision-maker (van der Steen et al., 2014). In this role the ‘best interests’ principle of the Mental Capacity Act (Department for Constitutional Affairs, 2007) highlights that a decision made must be done in the relative’s best interest, recognising all aspects of financial and personal welfare, but also healthcare decisions and actions.

Following their narrative analysis of families' perspectives of dementia end of life care, Davies and colleagues (2014) highlighted that there remains limited research on carers' experiences at this stage. They recommended that more information is needed from carers to provide a greater in-depth understanding. Yet frequently for these carers goals of care and end of life care decisions need to be made and the process of reaching these decisions can be significantly challenging. How prepared the family carers are to take on such a role and to be a best interest decision-maker needs greater understanding.

THE STUDY

Aim

The purpose of this qualitative study was to explore the experiences and preparedness of family carers who are responsible for best interest decision-making and caring of a relative living with advanced dementia.

Design

This descriptive qualitative study was part of a research project which evaluated an Advance Care Planning (ACP) intervention via a cluster randomised control trial (RCT), within 24 nursing homes in one region of the UK (Brazil et al., 2017) .

Participants of the research project were the primary carer of a nursing home resident with advanced dementia. They were informed that in addition to the RCT they would also be invited to complete a semi-structured individual interview with a member of the research

team (GC). These invitations continued until data saturation was reached (Guest, Bunce, & Johnson, 2006).

Sample and participants

In the participating nursing homes (all from one care home chain in the UK), resident records were reviewed by the nursing home manager to identify those individuals with dementia and judged as no longer having decision-making capacity. This was confirmed by the completion of the Functional Assessment Staging Tool (Reisberg, 1988; Sclan & Reisberg, 2005) by the nurse-in-charge. The family members recognised as most responsible for decision-making on behalf of these residents were identified as potential participants for the research project. Due to the staggered recruitment approach of the RCT, qualitative data saturation was reached after 20 individual interviews were conducted following contact with 31 participants, drawn from the first four participating nursing homes.

Data collection with family carers

Content of the interview invitation letter highlighted that participation would allow the family carer the opportunity to openly discuss their experience of being a carer for someone living with dementia and would also help to give a greater understanding of the impact of acting as a decision-maker. However, it was stressed that the participants were under no obligation to take-part. This invitation was mailed by the research team along with a participant information sheet and response slip. After completion of the response slip, carers were contacted to arrange an interview at a time and location most convenient to them.

All family carers' interviews took place in their individual relative's nursing home in a private room with minimal disruption. They lasted on average 30 minutes, were conducted in a sensitive manner and were audio recorded. All participants were provided with an information sheet detailing support and counselling services to contact if needed after their involvement in the study. A semi-structured interview schedule (Box 1) was developed from the literature, consultation with the research team and discussion in the study advisory committee.

BOX 1 Individual Interview Schedule

1. How would you describe the experience of being a carer for your *RELATIVE* in *NURSING HOME NAME*?
2. What has the experience of making decisions about your *RELATIVE'S* goals of care been like?
3. In your role as a decision-maker for your *RELATIVE'S* care planning, how much conflict including disagreements and negative feelings, has there been between you and the healthcare staff regarding your *RELATIVE'S* current and future care needs?
4. How well do you feel your GP and the nursing home staff recognise, value and understand your role as the primary carer and as a decision-maker for your *RELATIVE'S* goals of care?
5. Do you think there are things that could be changed or added in your nursing home to improve the experience of a carer who also has the role of decision-maker for their family member's goals of care?

Ethical considerations

To ensure anonymity of the participants, we removed all identifying characteristics of them, their relative and affiliated nursing home. Ethics approval was obtained from the regional Office of Research Ethics Committees Northern Ireland (Ref. 14/NI/0082) and the Queen's University Belfast Research Governance Office. Participants gave informed consent before taking part and signed a consent form.

Data analysis

The interviews were transcribed verbatim, checking against recordings for accuracy and then transferred to QSR NVivo11 where thematic analysis was completed by the first author using a recognised six stage framework (Braun & Clarke, 2006): familiarisation with data; generation of initial codes; searching for themes; reviewing of themes; defining and naming of the themes and production of a report. To ensure rigour the second author independently analysed transcripts using an electronic database of codes and quotations. Agreement on coding and themes were then reached through reflection and discussion (Holloway & Wheeler, 2010).

Rigour

Holloway and Wheeler's (2010) framework for establishing quality was followed to ensure trustworthiness of the data and analysis. To ensure consistency and stability, the first author completed all semi-structured individual interviews. Practicing reflexivity alongside peer debriefing allowed recognition for the potential influence of data interpretation of her own preconceptions and thoughts. Finally, an audit trail provided the rationale for decisions made

and reflections on the data analysis, further enforced by the establishment of inter-rater reliability.

FINDINGS

Of the 20 primary carers who completed an individual interview five were male and 15 female; the relationship of the resident was either parent (N=13), sibling (N=4), spouse/partner (N=2), or extended family (N=1). Interviews were conducted April – August 2015. Under an overarching theme of ‘Preparedness for Caring and Decision-Making Role’, three underpinning themes to reflect the experience of family carers responsible for decision-making for a relative living with advanced dementia were identified (Table 1).

TABLE 1 Underpinning themes and categories.

Underpinning Themes	Categories
1. Caring for someone living with dementia	<ul style="list-style-type: none">▪ Impact on holistic well-being of carer▪ Experience of being a best interest decision-maker
2. Accessing support	<ul style="list-style-type: none">▪ Family and friends▪ Other healthcare professionals▪ External resources▪ Nursing home partnership working with families
3. Perceived knowledge and understanding	<ul style="list-style-type: none">▪ Characteristics of the illness▪ Education and training▪ Systems and processes for end of life care discussions

Caring for someone living with dementia

This theme relates to the individual experiences of caring and coping alongside being a decision-maker for someone living with dementia.

The carers spoke of the enduring emotional stress they had or were continuing to experience. One respondent expressed their family's reaction to the diagnosis and the long-term implications:

“...the day mummy was diagnosed . . . my sister said to me that she wishes mummy had been diagnosed with cancer, would've been easier...and I thought 'how awful,

how could you say that?’ And now [I] know exactly what she means . . . it’s so true, it’s far harder for the people . . . far harder for the family, mummy’s content, she’s in her own wee world” (R01)

The conveyed stresses of the respondents’ situations were perpetuated by significant mental and emotional exhaustion and the inability to relax. One individual remarked that they had not had a holiday for five years. For some, their circumstance became too much for them to endure, which they admitted led to an over-reliance on alcohol. Nonetheless, it was revealed by the respondents that witnessing the gradual loss of the person that they once knew was the most distressing aspect:

“...she’s in this horrible limbo state and has been for a long time where she’s neither dead nor alive”(R19)

Additionally, guilt appeared to have a powerful influence on the carer. One respondent was very remorseful in admitting that using deceit was the only choice they had for their relative to accept long term formal care.

The experience of being a substitute decision-maker was highlighted as a substantial responsibility, with some recognising that this role was a natural progression for them as they had previously been the major decision-maker, or they were the only relative. For others, family circumstances or having a medical background meant that delegation came their way without discussion. Other decision-making rationales were a reflection of the carer’s personal circumstance, one family used a risk management approach, but ultimately the feeling of loyalty and responsibility for relatives was strongly expressed amongst all.

Prior to their admission to the nursing home the respondents either lived with their relative or nearby, however ensuring the safety of their relative was a key feature in this decision-

making process. This was coupled with the reported inability of the carer to continue to provide the level and intensity of care required, so the best interest choice was deemed to be formal care provision. For some this circumstance arose due to a hospitalisation from their own home following a medical emergency or because the situation was no longer manageable and the risk too great. The impact of transition into a nursing home was described as a combination of guilt, relief and, for some carers, continued anxiety:

“she’s literally out of the house, she’s out of my sight, she’s out of my control...and I find that really difficult”(R19)

There was a sense of failing their relative, amplified with sadness of handing their care over to someone else. Another individual described what was initially felt to be a difficult change for them to be followed by a realisation of how content their relative had become in the nursing home, which helped to lessen this carer’s distress at the decision made. This perceived reduction of anxiety over time was common among the carers. For most, the recognition that their relative was safe, happy, reasonably content and well looked after, helped to ease anxieties.

Accessing support

This theme highlights the reported levels of formal and informal support networks or resources available to the carers prior to and after the move to the nursing home and the influence on decision-making.

Some carers gave their first line of support and those they would initially turn to for assistance with decision-making, as their family and friends. However others felt this was not

an option, with previous friendship networks collapsing or strained relationships with family members causing conflict:

“It’s painful to watch someone completely change. And it’s isolating because . . . we’d a big circle of friends and slowly but surely everything just disappeared. People came, kept calling for a little while and then one by one they faded away”(R05)

Incidences of perceived poor support as a reflection of conflict with some health care providers or an alleged lack of adequate social support were revealed, subsequently making the individual feel less inclined to approach the healthcare staff for support. Similarly, healthcare professionals unfamiliar with the family and the resident’s individual wishes were also noted to cause unnecessary anxiety, again resulting in reluctance of further contact. In one case, poor communication from a consultant resulted in a self-diagnosis of dementia as no information was forthcoming with the presumption instead that the carer and their relative with dementia were already aware. Despite these negative reports, recognition of excellent compassionate and supportive care were given, alluding to social workers, GPs, nurses and formal carers.

External support resources from the community or charitable organisations were a key feature for some. Specifically, reliance on neighbours or being members of a close community gave reassurance of their relative’s safety when they were not present and volunteering with dementia organisations was seen as a rewarding and supportive experience, but also one that enhanced the relationship between family carers as the decision-maker with professional care providers. Nonetheless, others were hesitant at approaching such organisations concerned that they would be seen as a fraud due to the specific diagnosis of their relative’s dementia.

Unfortunately, a sense of disillusionment of where to seek help was also reported:

“...there isn’t an advice centre you can go and have a chat . . . where do you go, it’s not citizen’s advice, it’s not cruse bereavement”(R14)

In the nursing home environment, friendships were noted to naturally develop with other residents and their families. Nursing home staff were also recognised and commended for their support by carers. It was felt that the staff and affiliated GPs recognised the decision-making role of the carers; in particular the continual communication with updates and feedback on the resident’s care was welcomed. Even so, due to an alleged frequent turnover and shortage of staff, confidence with this line of support was diminishing for some.

The discussion of having access to family forums in the nursing home was appealing. One respondent noted that their nursing home manager held such events giving the opportunity of open questioning and peer support, allowing shared experiences of care and decision-making processes to be discussed. Nonetheless, ambivalence remained, highlighting that the support sought reflected the individual needs of the person and a preference for individualised support.

Perceived knowledge and understanding

This theme encapsulates the level of awareness for the characteristics of dementia held by family members, including the perceived availability of education and training for family carers and health care staff and the systems and processes in place for end of life care discussions.

Past experience of caring for another relative with dementia was the foundation of knowledge for some carers. Few had a medical or nursing background which aided their understanding; nonetheless, a distinct lack of awareness of the disease was generally perceived:

“Dementia starts as this mental illness and then becomes a physical one, again ye don’t know it until ye go down that road . . . I just don’t think there is enough awareness of this horrendous illness”(R19)

Educating family carers about dementia was often raised. It was felt that advancement of knowledge would allow some anticipation of the disease’s progression:

“I don’t think some of the stuff you need to know is easily available and I think the more anybody can do to further the knowledge and the understanding so you get there quicker and sort things out as soon as you can to give that person the best quality of life they can have [the better]”(R13)

The perceived level of training completed by the staff was also questioned in relation to their preparedness for caring for someone living with dementia. Some respondents were particularly perturbed by the discontinuity of staff and their perceived lack of dementia expertise:

“...make sure that the staff. . .have been properly trained, not trained on the job but go through. . . an intensive week. . .give them some idea because they haven’t a clue about dementia.”(R20)

For the majority of respondents, decisions with regards to goals of care for the end of life was a topic that had not previously been discussed. As such the respondents alluded to the challenge they faced and the need for preparedness to take part in best interest decision-making. Lack of awareness of implications of the disease progression was a reason given for not approaching such discussions but, it was also considered a somewhat taboo matter. Some

carers commented that they did try to broach the subject with their relative but without success, resulting in decisions being made on their behalf:

“we tried to talk to mummy about what care she would like further down the line, but she never discuss it . . . she just wouldn’t get into that conversation...and I suppose just when we had to start making those decisions mummy was beyond having any input really in it”(R01)

It was also reported that the nursing home staff had up to this point not raised the subject. It was felt to be a topic that was avoided and there was uncertainty whether this was a reflection of the nursing home staff knowledge and training. But those that had been in the position to discuss end of life choices with their relative and or with healthcare staff, felt such discussions had made best interest decisions less burdensome. For others, such conversations held before diagnosis or by following their relative’s personal philosophies allowed self-assured choices to be made.

DISCUSSION

The findings of this study provide insights into the preparedness and experiences of family carers responsible for decision-making on behalf of a relative living with advanced dementia which can inform practice, family carer and formal carer education and further research.

Caring for someone living with dementia

Similar to previous international research regarding family carers, decision-making and end of life care, participants in this study had experienced carer burden which appeared to affect them on a whole person level (Hudson & Hayman-White, 2006; Hudson, Thomas, Trauer, Remedios, & Clarke, 2011; Payne et al., 2010). This indicates the need for family carers of

people with dementia to be offered holistic care and support including in the nursing home setting. At a European level psychosocial support required by family carers is a key recommendation of a European Association of Palliative Care (EAPC) White Paper which defines best practice in palliative care for people with dementia (van der Steen et al., 2014). They suggest a model of changing care goals and priorities throughout the course of the illness, reflecting the changing significance of care goals at different dementia stages. Consequently decision-making is recognised as not being a one-off choice but one that involves different individuals at different points in the caregiving trajectory and in various care facilities (Jones et al., 2016). Our respondents recognised when their individual circumstances altered in conjunction with the needs of their relative and it can be argued that their sense of identity and of role could be guiding influence on the outcome (Burke & Stets, 2009), as role implementation can be defined by caregiving demand and preparedness for caregiving (Huang et al., 2015). Some respondents found this role change significantly challenging and recognition of such changes needs ongoing appreciation by healthcare staff (Anesbensen, Pearlin, Mullan, Zarit, & Whitlatch, 1995).

In our study, carer burden was generated by family members' inability to escape from the constant stress and responsibility of caring for their relative; as a result they did seek their own personal and sometimes adverse coping mechanisms. Manifesting in different forms, stress was predominately reported though the premature loss experienced as they witnessed their family member irreversibly change. Anticipatory bereavement offers a way of understanding such an expected loss (Coombs, 2010; Evans, 1994), highlighting that this carer population may be exposed to loss and bereavement in a different and earlier way than family carers of people on other end of life disease trajectories. While decisions regarding end of life care goals do attempt to lessen such burden, carers can experience extreme

challenges in justifying care goal decisions as these often occur whilst experiencing anticipatory grief (Black et al., 2009; Jones et al., 2016).

A recent systematic review focusing on proxy decision-making by family carers of people with dementia reveals the distress they can experience in making decisions for their relative and the need for increased support from healthcare professionals to facilitate this process (Lord, Livingston, & Cooper, 2015). Individual circumstances for our participants drove their decision-making process and response. It was also apparent that there was a lack of previous discussion around end of life issues and decisions on care goals with family members. This suggests a need for ongoing training of professionals and more preparedness and education of family carers, which has been highlighted in supporting research (Ashton, Roe, Jack, & McClelland, 2016; Huang et al., 2015).

Accessing support

Participants reported varying experiences of accessing support. Whilst there were positive accounts of support received from formal carers prior to their relative's admission to the nursing home, some participants reported they were unsure where to obtain support and advice. Strong peer support could naturally occur with family members of residents in the nursing home. Such social support mechanisms can buffer the psychosocial stress of being a carer and the subsequent readjustments to changes in circumstance as reported in the seminal work by Cohen and McKay (1984). These networks not only have the potential to contribute to an individual's sense of identity and provide a resource for comfort (Sluzki, 1992), but they are also crucial in the decision-making role of the carer. The perception of support,

connections with and actions of others to elicit assistance, highlight the dynamic nature of social support and the potential influence of individual personal requirements (Barrera, 1986; Vaux, 1988).

The concept of family forums in nursing homes could also play an important buffering role. This naturally developing support structure has implications for the delivery of palliative care psychoeducational support. A systematic review of family carer interventions in a palliative care context highlights the need for robust empirical research to determine strategies which best support and help family carers in different contexts (Hudson, Remedios, & Thomas, 2010). Our findings suggest that for family carers of people with dementia residing in nursing homes psycho-educational care interventions, containing facilitated peer support, could be of significant value.

The importance of promoting a person-centred approach to decision-making whilst acknowledging the pivotal influence of a trusting relationship between family carers and healthcare professionals is essential (Ashton et al., 2016). Partnership working between family carers and nursing home staff is a significant aim in policy and practice (Department of Health 2010). Not only does it enable the development of therapeutic relationships, it is a powerful approach allowing nursing home staff to provide more helpful and sustainable care for the resident by recognising the family carer expertise (Watkins et al., 2011). Shared decision-making with family carers and with the person with dementia where possible, is a key aspect of recognised international practice in palliative care provision for this population (van der Steen et al., 2014).

Perceived knowledge and understanding

There was diversity in the perceived level of knowledge and understanding of the dementia trajectory and how to care for someone with this condition. This highlights a need for family carer education and the provision of anticipatory guidance to promote a better sense of preparedness for this caring role and best interest decision-making. Specifically, the need for family carer education in relation to the disease progression and appropriate treatment options for people with dementia has been recognised (van der Steen et al., 2014). A recent UK ethnographic study found that both family carer and formal carer education on dementia progression is needed to promote conversations about end of life (Saini et al., 2016). There is also a responsibility for formal carers to sensitively normalise discussions about dying to enable appropriate care planning and decision-making (Black et al., 2009). However, the influence social and cultural aspects have with death as a taboo subject needs to be recognised. The US National Research Council (2010) reported that contextual determinants influence what kind of adaption families believe to be reasonable in end of life care suggesting that person and family centred care is fundamental.

Participants perceived a lack of dementia knowledge and skills around caring for people with dementia amongst nursing home staff. They felt that more education and training needed to be targeted at formal carers in nursing homes to develop their competence in caring for this population. This requires education founded on the EAPC's 11 domains of best practice in palliative care provision for people with dementia and their family carers (van der Steen et al., 2014). There is also evidence from a Canadian study that health care professionals who are able to demonstrate knowledge and expertise can more effectively initiate discussion and facilitate decision-making with family carers of people with dementia (Torke, Schwartz, Holtz, Montz, & Sachs, 2013). Additionally it is known that family carers need a whole

family approach to consult with and be reassured following a best interest decision (Livingston et al., 2010). Some participants commented that no staff from the nursing home had engaged in an end of life care discussion with them in relation to their family member, which further supports the need for trainings.

Participants perceived a lack of discussion and openness about end of life issues among family carers themselves and with the resident prior to their nursing home admission. A recent narrative synthesis on quality end of life care for dementia (Davies et al., 2014) identified the theme of 'family carers' ability to think about death and dying' highlighting the extreme difficulty some carers have at approaching this subject. This research tallied with the perceptions that professionals have about families' reluctance to discuss planning for end of life care (Stewart, Goddard, Schiff, & Hall, 2011), nonetheless a negotiated understanding of shared perspectives has been noted to improve communication between healthcare staff and family carers (Caswell, Pollock, Harwood, & Porock, 2015). Being able to have an early discussion with their relative about end of life issues made things easier for some participants but this was not the norm for others as the opportunity had not been possible. The National Institute for Health and Care Excellence (2010) promote early decision-making noting that people living with dementia, while they have capacity, have the opportunity to discuss and make decisions, together with their carer(s) but this is dependent on healthcare professionals being appropriately trained to facilitate such discussions.

Strengths and limitations

A particular strength of this study is the individual interviews held with current carers of individuals living with advanced dementia and residing in a nursing home. Conducting semi-structured interviews allowed individuals to reflect on issues important to them and provided the context of their previous and current experiences. However a possible limitation is that those who completed the individual interviews were a self-selected sample, 12 of which were exposed to an ACP intervention which may have guided the respondents thinking. However, any specific responses to the ACP intervention were not incorporated in the reported results.

CONCLUSION

This study explored the experiences and preparedness of family carers responsible for decision-making on behalf of a relative living with advanced dementia and residing in a nursing home. Being a multifaceted role, carers' preparedness for this was a reflection of their personal response, but the distress experienced highlighted the significance of adequate support availability to suit their needs. Enhancing the nursing staffs' dementia expertise to maximise their role of facilitating best interest decision-making and end-of-life care discussions with family carers, is crucial to enable this supportive relationship. Consequently, these findings have implications for nursing practice and for education of service users and healthcare staff. In particular there is a need for the development of family carer psycho-educational care interventions, with embedded facilitated peer support, to help prepare this population for best interest decisions alongside training for healthcare staff and management to facilitate these discussions. Given the global impact of dementia and that most people with dementia receive end of life care in nursing homes, findings have international relevance for similar nursing homes across the world.

AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria

[recommended by the ICMJE (<http://www.icmje.org/recommendations/>)]:

- Substantial contributions to conception and design, acquisition of data or analysis and interpretation of data
- Drafting the article or revising it critically for important intellectual content.

CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

FUNDING

This work was supported by Health and Social Care Public Health Agency Northern Ireland and The Atlantic Philanthropies. The funding source had no involvement in the study design, in the collection, analysis and interpretation of data, in the writing of the report; and in the decision to submit the article for publication.

ACKNOWLEDGEMENTS

The authors wish to express their sincere thanks to all of the family carers who participated in the interviews.

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